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“You have to change your whole life”

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SUPPLEMENTARY MATERIAL

Karat et al. *"You have to change your whole life": a qualitative study of the dynamics of treatment adherence among adults with tuberculosis in the United Kingdom*

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"You have to change your whole life": a qualitative study of the dynamics of treatment adherence among adults with tuberculosis in the United Kingdom

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Appendix 1: Additional methods

Supplementary table 1. Inclusion and exclusion criteria used to select participants for formative interviews

Participant group	Inclusion criteria	Exclusion criteria
Patients	<ol style="list-style-type: none">1. Age \geq 18 years2. Suspected to have TB disease or has previously taken treatment for TB disease3. Able to provide informed consent	<ol style="list-style-type: none">1. Unable or unwilling to provide informed consent
Caregivers	<ol style="list-style-type: none">1. Age \geq 18 years2. Involved in caring for or supporting someone currently taking (or who took in the past) treatment for TB disease*3. Able to provide informed consent	<ol style="list-style-type: none">1. Unable or unwilling to provide informed consent

*In practice, individuals were approached only if the person they were/had been caring for gave verbal permission for the study team to do so.

TB: tuberculosis

Sampling and recruitment

Attempts were made to interview roughly equal numbers from each NHS Trust and to ensure reasonable representation by sex and ethnicity. Additional efforts were made to include patients without English as a first language. Patients were identified by HCPs in their TB service and asked to take part; individuals were approached who had encountered difficulties with adherence and who had taken treatment without too many apparent problems. Interviews with caregivers were difficult to arrange, as permission was required from the patient to approach a caregiver; on some occasions, nurses arranged for a patient and caregiver to attend together and to be interviewed in succession.

Potential participants were approached, given a brief overview of the study, and asked, usually by a specialist TB nurse, about their willingness to be interviewed. If they agreed, potential participants were provided with a copy of the participant information sheet (PIS) and informed consent form (ICF) to review at their leisure. Written informed consent was obtained from each individual prior to data collection.

Consent and anonymisation

Prior to interview, all participants were provided with information sheets detailing the objectives of the study and their rights as participants. The researchers reviewed the information sheet with each participant prior to the start of the interview and obtained written informed consent from each participating individual. Each participant was assigned an identifying number to ensure anonymity. Pseudonyms are used in the manuscript to humanise accounts and quotes; no information that could potentially identify a participant has been included.

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Data management and protection

When participants gave permission, interviews were audio recorded using an Olympus DS-9500, which stores audio in an encrypted file format that can only be opened using software for which a license has to be purchased. Audio files were transferred from the recorder to a password-protected computer immediately after completion of the interview and backed up on an external, password-protected USB drive, which was also used to transfer audio files between password-protected computers. Signed consent forms were stored in a locked cabinet. As soon as possible after an interview, any hand-written notes were scanned, the file password-protected, and the original destroyed.

Interviews were transcribed in two steps: 1) a 'first pass' through voice recognition software provided by <https://www.happyscribe.co> and 2) manual checks and cleaning using InqScribe software (<https://www.inqscribe.com>).

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Topic guide: patient interviews

Thank you for agreeing to be interviewed. We are interviewing individuals who are currently or recently have been on TB treatment in order to understand their pathways to care, and the issues they may face while being on treatment. We are conducting interviews with both health providers and patients attending this facility, as well as doing some observations to better understand how patients like yourself experience care in this facility. The questions we will ask you today are focused on your TB care journey, with particular emphasis on how things have been for you since starting on treatment. We value your reflections on your own experience and your thoughts on what, if anything, is needed to improve your care here. As already mentioned in the information sheet and consent form, the interview will take approximately one hour of your time. Please do feel free to ask any questions now or during the interview itself.

Patient profile

- Please tell me a little bit about yourself and what brings you here today (*probes can include e.g. current health, place of origin/residence, length of residence in current location, employment/occupation*)
- Do you have any family here? Can you tell me a bit about them? (*probe: do they live with you/how many people do you live with; from where is your family originally?*)
- How is your health at the moment? How do you feel? (*probe: any physical symptoms?*)
- What has been your experience of seeking health care in this city? (*probe regarding experience of NHS if from outside the country*)
- What have you found positive during this experience? What have you found negative? (*probe on access, transport, ease of finding services*)

Pathways to TB treatment and care

- Tell me about when you first started feeling symptoms that led you to seek care? OR
- When were you first screened for TB? Can you recall the experience? (*probe: tell me more about it, what were the circumstances?*)
- What happened next? How were you diagnosed? (*probe: how you were informed? who did this, in which facility, how long did they take to explain the diagnosis and treatment?*)
- Tell me about when you started coming to this clinic for your treatment (*probe for original first impressions, ease of access, general feelings at the time*)
- Is there a typical time of day you prefer to visit the clinic? How long does it take you to travel here?
- Do you have to spend money to come to clinic?
- How long are you normally in the clinic? (*probe on how much time out of the day is required to receive treatment; what would you normally be doing if not having to go to the clinic?*)
- Are there disadvantages to having to come to this clinic? Advantages?

Treatment adherence issues

Knowledge and perceptions of TB and TB treatment regimen

- What does TB mean to you? (*probes: what did you know about TB before you found out you had the disease? What do you associate the condition with now?*)
- Had you known anyone before who had been diagnosed with TB?
- Tell us about your treatment regimen (*probe on patient knowledge of dose and duration*)
- Who presented you with this information? What did they tell you?
- What do you think about the TB treatment you have been prescribed?
- What is your understanding of how the treatment works?
- Do you have any concerns about the treatment?

TB medication adherence

- How have you felt on this treatment? (*probe on different stages of treatment*)
- What makes it easy/difficult for you to take these medicines regularly? (*probe on social/environmental challenges*)
- How important do you think it is for **you** to follow the prescription?
- What is your understanding of what happens if someone does not take their TB treatment correctly? (*probes: what is your knowledge regarding the consequences of non-adherence e.g. resistance, treatment failure etc.*)?

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- Do you forget to take the drugs sometimes? What are the reasons for forgetting?
- Do you worry when you haven't taken your medicines? Do you talk to anyone about it?
- Have there been times when you preferred not to take the drugs? (*probe: e.g. if the side effects would interrupt important events/plans you have on a particular day*)
- Tell me about any times that you struggled you take your medication as prescribed. What caused this? How did this affect your adherence? (*probes: did you stop taking your treatment before the end? Did you take your medication later in a day? Did you not take your doses on certain days of week?*)
- Have you ever made an active choice that you didn't want to take your medicines?
- *If yes to above question:* at what point did you make that decision? What was the reason for not taking the medicines

Social support

- How do you cope with your illness on a daily basis?
- When you are sick, is there anyone in particular who looks after you/supports you?
- If yes – who is this person? How do they support you? (*probe: psychological, social, financial*)
- Are there members of the family or other social contacts who know about your illness? If so, have you been able to talk to them? (*probes: who did you talk to? how did they react? how did you feel telling them about your diagnosis/illness?*)
- How often do you see family? What about friends? Has anything changed since you were diagnosed with TB?
- Do you feel that anything has changed for you in terms of your social life since being on TB treatment?
- Do you know other people on treatment? If yes, do you discuss how you feel with them? If yes, you do discuss how you feel, is this helpful to you? If no, why not?
- Has there been anyone who helps you stay on track in terms of your treatment?
- Are any people or organisations providing you with regular advice or support during your treatment?
- If so, how do they help you? How do you feel about this help? (*probe: is it welcome? embarrassing or inconvenient?*)
- Are there any types of advice or support that you need during your treatment and which you are not currently receiving?

[question to identify social contact interviewee] Is there a family member or someone who you are close to whom we could interview? We would like to gain their understanding of the issues in supporting you whilst on treatment. We would be very grateful for the opportunity to speak to them.

Structural and health systems issues

- Tell me more about your visits for treatment. How many staff members would you say you come in contact with each time? For how long with each?
- Do you ever feel you need more/less time with clinic staff?
- How do you feel you are treated when you come in (*probe on whether it is a personable or welcoming experience?*)
- Do you find it easy to get around the clinic?
- Can you give me any examples of a situation that would make it difficult for you to visit the clinic for your treatment (*probe on traffic, work, illness*)? What would you do in this case? (*probe on whether they inform the clinic or if clinic contacts them first*)
- In what ways does the clinic support your treatment currently? What are they doing to help you stay on treatment?
- What are your perceptions of the ways staff interact with you or other patients? Do you feel there is strong communication? Do you feel sufficiently supported? (*probe on patient/staff rapport, communication content, language issues, staff communication style, is it sufficient/easy to reach out to staff members if necessary?*)
- Can you recall any instances where you felt that the clinic staff was unavailable to you?
- How important do you think it is to be in regular contact with your treatment team?

Perspectives on intervention

- Finally, are there any lessons gained from your experience of being on TB treatment that you could share with others who are starting treatment?

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- Can you think of anything more that you would have liked to know or would have been helpful to have been explained to you when you were diagnosed?
- What could be improved in the service to support people like you on treatment?
- What could be done differently in this clinic? (*probe on access, opening hours, finding one's way through clinic, communication, care*)
- Do you have any examples of things that you have done/found useful which have helped you to take your treatment correctly and consistently?
- If there was a technological way to help you take your medication (for example, a phone app) would that have been helpful? What sort of things do you think technology could do to help people taking TB medication?

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Topic guide: caregiver interviews

Thank you for agreeing to be interviewed. We are trying to understand more about individuals' experiences of being on TB treatment and the issues that might lead them to interrupt or stop taking treatment altogether. In addition to talking to individuals who are currently on treatment or have been on TB treatment in the past, we are also conducting interviews with people who are involved in the care and support of these individuals. We asked them about the support they receive, and whether there was someone who they felt helped them in their experience of having TB and being on treatment. This is how we were able to contact you. The questions we will ask you today are focused on your role in the support of [index case] and your thoughts about what might help patients like [index case] to stay on treatment. We value your reflections on your own experience and your thoughts on what can be done to improve the lives of individuals on TB treatment. As already mentioned in the information sheet and consent form, the interview will take approximately one hour of your time. Please do feel free to ask any questions now or during the interview itself.

Social contact profile

- Please tell me a little bit about yourself and your situation (*probes can include place of origin/residence, length of residence in current location, employment/occupation*)
- What is your relationship to [index case]? If not related, ask: how long have you known x, and in what capacity?
- When did you find out about x's current diagnosis of TB?
- How did you find out?

TB knowledge

- When you found out about x, did you know anything about TB?
- If yes, what did you know?
- Has your understanding of the disease changed since you found out about x?
- What do you know about the treatment x is taking? (*probe on medicines, doses, side-effects, duration of treatment*)
- How did you find out about TB when you knew about x? (*probe: sources, individuals*)
- Do you feel you have enough knowledge about TB to be able to support x?

Social support role

- In what ways has having TB affected x? What changes have you noticed in him/her personally?
- How has it affected the household (if family)?
- How has it affected x's social life?
- What kind of help or support do you give x? (*probe: financial, accompanying to health clinic, help at home, emotional support*)
- How do you feel about this role? What are the challenges?
- Has helping/supporting x on treatment affected you personally?
- Have you noticed times that x had particularly struggled to take their medication?
- What are the reasons x might stop taking treatment? Does x tell you about times when he/she has interrupted or stopped treatment?
- What are the ways you or others encourage him/her to stay on treatment?
- Have you been contacted by anyone from the clinic x attends? Have you been in contact with anyone from the clinic? If so, for what reason?
- How do you feel about the care x is receiving from this clinic?

Perspectives on intervention

- What has been positive about your experience of helping/supporting x on treatment?
- What has been most challenging?
- What would make the most difference in terms of being able to support x better? Are there specific things you feel that you need to better help x stay on treatment?
- What do you think the role of the clinic should be versus the role of the family/social network? Who should take the lead in supporting patients like x? Why?

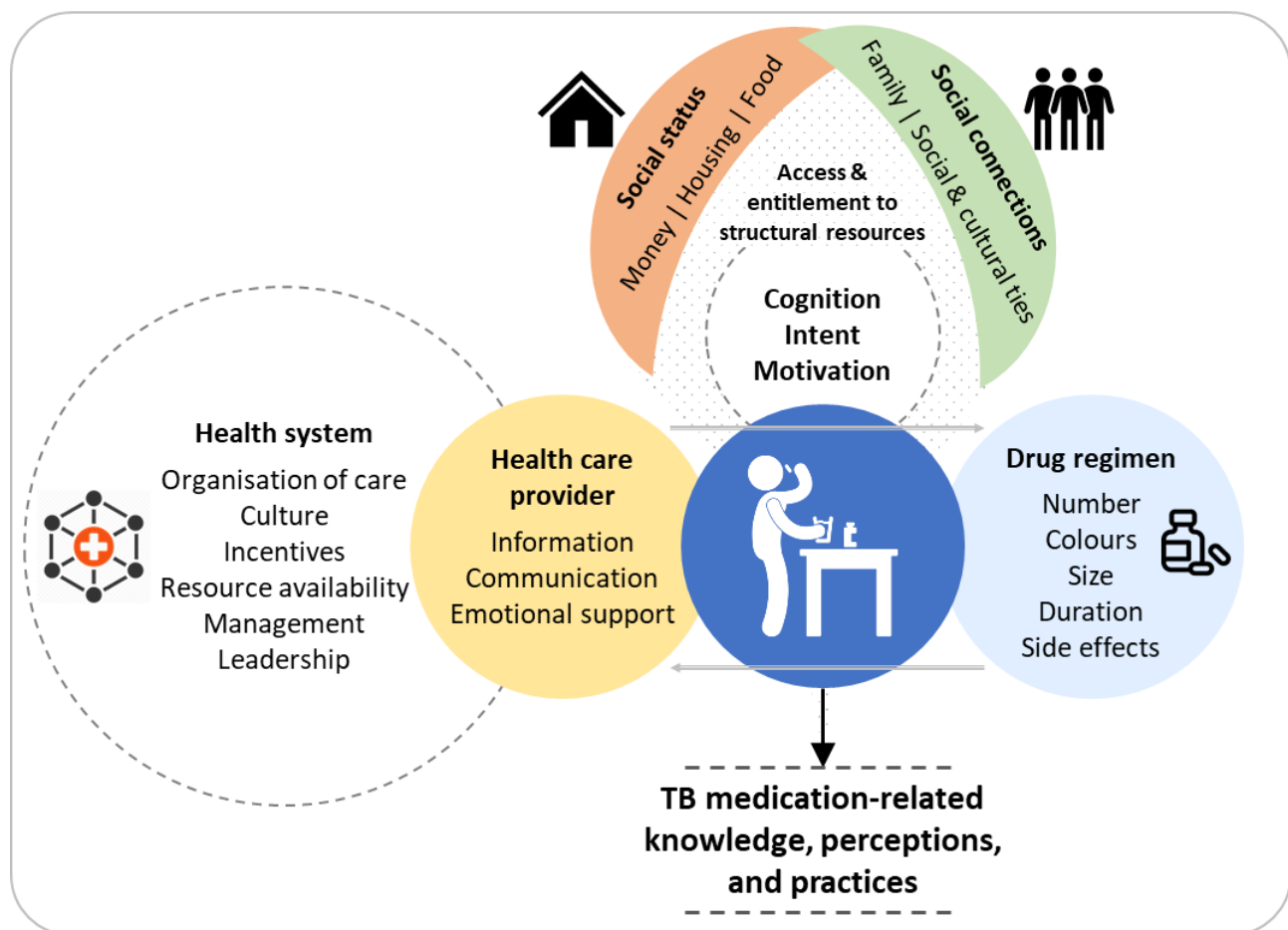
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Conceptual framework

This framework built on findings of the 2007 systematic review by Munro et al.¹ and a 2019 scoping review² to classify determinants of adherence broadly as personal, social, structural, health systems, or treatment-related. Supplementary figure 1 illustrates how some of these elements might interact with each other and influence an individual taking ATT, with their overall effect seen outwardly as 'knowledge, perceptions, and practices'.

Supplementary figure 1. Conceptual framework informing a relational view of adherence to medication for TB



TB: tuberculosis

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Appendix 2: Additional results

Supplementary table 2. Pseudonyms and characteristics of patients (n = 18) and caregivers (n = 4) interviewed

#	Pseudonym	Description	Interviewed by
Patients			
1	Rita	Female, 30s, from South Asia.	AK, KK
2	Henry	Male, 60s, from Southern Africa.	AK, KK
3	Alastair	Male, 50s, from the UK.	AK
4	Michael	Male, 50s, from the UK.	AK, MD
5	Eunice	Female, 20s, family from the Caribbean.	AK, AJ
6	Janella	Female, 20s, family from East Asia.	AK
7	Suchin	Female, 60s, from East Asia.	AK, AJ
8	Yousuf	Male, 30s, family from East Africa.	AK, KK
9	Ahmed	Male, 20s, from South Asia.	AK, KK
10	Imran	Male, 20s, family from Central Asia.	AK, AJ
11	Gopal	Male, 30s, from South Asia.	AK, AJ
12	Aalok	Male, 40s, from South Asia.	AK, AJ
13	Arif	Male, 50s, from South Asia.	AK
14	Salman	Male, 20s, from South Asia.	AK
15	Zhen	Male, 20s, from East Asia.	AK
16	Vidya	Female, 20s, from South Asia.	AK, AJ
17	Naomi	Female, 50s, from the UK.	AK, AJ
18	Yasir	Male, 40s, from East Africa.	AK
Caregivers			
1	Jaya	Female, 40s, from South Asia. Wife of Arif.	AK
2	Aileen	Female, 50s, from the UK. Wife of Alastair.	AK
3	Gauri	Female, 40s, from South Asia. Cared for her husband (who was not interviewed)	AK
4	Nadia	Female, 20s, family from South Asia. Wife of Salman.	AK

AJ: Annie Jones; AK: Aaron Karat; KK: Karina Kielmann; MD: Marcia Darvell; UK: United Kingdom

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